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## Case Study: The Parkinson's Experience

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# Case Study: The Parkinson's Experience

## **Abstract**

Previous research has extensively studied individual components of Parkinson's by studying the disease but thus far does not address the comprehensive impacts and obstacles of life with Parkinson's. The common experiences of Parkinson's can offer insight as to how provide better care by addressing multiple domains in a person's life. This hypothetical case study highlights commonalities shared by those with Parkinson's that spans across social, emotional and biological aspects of life. Possible treatment strategies are discussed concerning the impacts of fatigue, social isolation, increased burdens of care, and family dynamics in order to offer insight to care providers as to the range of care needed by those with Parkinson's disease. The goal of this article is to highlight that, while interventions are needed to address the disease, providers should be mindful that interventions are also needed to limit the negative impacts of Parkinson's on a person's life experience.

## **Keywords**

Parkinson's disease, Fatigue, Burden of Care, Medicare, Social Isolation, Symptoms, Social Work, Palliative Care, Case Study

## **Cover Page Footnote**

"For everything this disease has taken, something with greater value has been given – sometimes just a marker that points me in a new direction that I might not otherwise have traveled. So, sure, it may be one step forward and two steps back, but after a time with Parkinson's, I've learned that what is important is making that one step count; always looking up." - Michael J. Fox, 2009. *Always looking up: The Adventures of an Incurable Optimist*. New York, NY: Hyperion

## Case Study: The Parkinson's Experience

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Previous research has extensively studied individual components of Parkinson's by studying the disease but thus far does not address the comprehensive impacts and obstacles of life with Parkinson's. The common experiences of Parkinson's can offer insight as to how provide better care by addressing multiple domains in a person's life. This hypothetical case study highlights commonalities shared by those with Parkinson's that spans across social, emotional and biological aspects of life. Possible treatment strategies are discussed concerning the impacts of fatigue, social isolation, increased burdens of care, and family dynamics in order to offer insight to care providers as to the range of care needed by those with Parkinson's disease. The goal of this article is to highlight that, while interventions are needed to address the disease, providers should be mindful that interventions are also needed to limit the negative impacts of Parkinson's on a person's life experience.

*Keywords:* Parkinson's disease, Fatigue, Burden of Care, Medicare, Social Isolation, Symptoms, Social Work, Palliative Care, Case Study

A life with Parkinson's disease is a life of uncertainty and obstacles brought on from both motor and non-motor symptoms. Not every Parkinson's experience can be captured by a single story or timeline of symptoms. Parkinson's disease is not a single symptom experience. Those with this disease have multiple symptoms that present in a variety of manners all compounding in daily life (Poewe, 2008). Research has extensively studied factors of Parkinson's disease like physical presentations, mental health, and the effects of social support individually, but thus far only a few focus on the comprehensive impacts and obstacles of life with this disease (Boland & Stacy, 2012; Cohen, Underwood, & Gottlieb, 2000; Dobkin, Menza, Allen, Gara, Mark, Tiu, Bienfait, & Friedman, 2011; Janevic, Rosland, Wiitala, Connell, & Piette, 2012; McComb & Tickle-Degen, 2005; Ransmayr, 2011; Poewe, 2008; Schapira, 2005; Schreurs, De Ridder, & Bensing, 2000; Simpson, Faines, Lekwuwa, Wardle, & Crawford, 2006). The nature of Parkinson's disease is such that there is no guarantee of symptom severity or which symptoms may present. However, there are common experiences among those with Parkinson's that can offer insight to this progressive and currently incurable disease. With this in mind, this paper addresses multiple domains and potential experiences of Parkinson's disease and the impacts this disease may have on one's life. Using a fictional case study, this paper will take a person through the social, emotional, and biological aspects of living with Parkinson's.

### Review of Literature

#### What is Parkinson's disease?

Parkinson's disease is a degenerative condition named after the English doctor, James Parkinson, who

helped refine descriptions of the physical presentations associated with this disorder in his published work titled "An Essay on the Shaking Palsy" in 1817 (Burch, & Sheerin, 2005). Since then, Parkinson's disease has been studied extensively and found to be an idiopathic (cause unknown) loss of cells in the region of the brain known as the substantia nigra which are responsible for producing dopamine (World Health Organization, 2006). Dopamine is the neurotransmitter for signals to control and coordinate movement. In Parkinson's, the loss of dopamine reduces the ability to directly control motor function (Parkinson's Disease Foundation, 2013). Parkinson's disease currently has no known cure.

#### Who is affected by Parkinson's disease?

According to a survey by the World Health Organization (2005), there are an estimated 5.2 million diagnosed cases of Parkinson's disease worldwide, and of those an estimated 1.2 million cases are in the United States (World Health Organization, 2006). Future estimates, given the number of newly diagnosed cases each year and the incurability of the disease, put the United States near 1.8 million diagnosed cases by 2030 (Boland & Stacy, 2012; World Health Organization, 2006). While many studies argue an indiscriminate distribution of Parkinson's disease across gender and ethnicity, one study found significant data to support their findings that incidences of Parkinson's are more prevalent in males, non-Hispanic whites, and that the risk for diagnosis increases with age (Van Den Eeden, Tanner, Bernstein, Fross, Leimpeter, Bloch, & Nelson, 2003). The typical age range for a confirmed diagnosis is around one's fifties or sixties. However some are diagnosed sooner which is known as early onset Parkinson's (World Health

Organization, 2006). These figures are only representative of clinically diagnosed cases and do not include people who are living with the disease yet to be diagnosed due to either the lack of health care availability or the reduced symptom severity typically found in early onset stages.

### Pre-Diagnosis

Prior to diagnosis a person may become aware of unexplained symptoms, or changes in posture, memory, or gait. Researchers suggest that one reason for the delay in consulting a doctor may be due to the lengthy onset of symptoms, role changes, and cognition decline often mistaken for the natural decline of the physical body (Wressle, Engstrand, & Granerus, 2007). When under the care of a doctor, a comprehensive medical history along with a thorough neurological assessment is first taken in order to rule out other possible explanations before Parkinson's can be diagnosed (Michael J. Fox Foundation, 2012). It is estimated that by the time motor symptoms present themselves, 60% of dopamine neurons in the brain are lost or destroyed (Adler, 2011).

It is not uncommon for those seeking treatment for Parkinson's-like symptoms to see a neurologist along with their primary care provider in order to have a collaborative effort when diagnosing possible causes for their symptoms (McLaughlin, Hasson, Kernohan, Waldron, McLaughlin, Cochrane, & Chambers, 2010).

### Motor/Non-Motor Changes Associated with Parkinson's disease

When surveyed about the most common symptoms associated with Parkinson's, people often report the symptoms that have an outward presentation such as bradykinesia, tremors, erratic movements, and rigidity (Burch & Sheerin, 2005; European Parkinson's Disease Association, 2008). Research suggests that as motor symptoms worsen, activities of daily living like getting out of bed, brushing one's teeth, or going to the bathroom require greater amounts of concentration or assistance (McLaughlin, et. al., 2011; Platt, 2004). As mentioned before, by the time motor symptoms appear approximately 60% of dopamine neurons are lost (Adler, 2011).

Along with motor symptoms, those with Parkinson's disease may also experience what are called non-motor symptoms. Non-motor symptoms include cognitive, psychological, and emotional changes due to the destruction and slowing of neurons and synapses in the brain (Barbas, 2006). Due to the destruction of neurons and slowing of synapses, actions in the brain that normally occur without much effort (e.g., basic math, word recognition, and memory recall) may become more difficult, often resulting in states of confusion (Barbas, 2006; Platt 2004; Wressle, Engstrand & Granerus, 2007).

Another problematic occurrence of Parkinson's disease can be described as the On-Off phenomenon

(Haahr, Kirkevold, Hall, & Ostergaard, 2011). "On" can be describes as when motor and non-motor symptoms are under control either through medication or having a good day. "Off" can be attributed to episodes of severely decreased mobility, rigidity, cognitive impairment, or tremors and is common when medications start to wear off or perceived stress is too much, allowing for such symptoms to take control. The on-off phenomenon may happen randomly or regularly depending on the progression of the disease, stress, and medication schedules (Haahr, Kirkevold, Hall, & Ostergaard, 2011).

### Concerns about the Future

A successful diagnosis of any disease may bring a sense of great relief and validation over the health concerns a person may have (Haahr, Kirkevold, Hall, & Ostergaard, 2011). However, as with any diagnosis, Parkinson's can also bring feelings of fear, uncertainty, and frustration (Haahr, Kirkevold, Hall, & Ostergaard, 2011; McLaughlin et al., 2011). These feelings of fears are often reported as concerns over what the future will be like with this disease and in what capacity the symptoms will leave them in (Haahr, Kirkevold, Hall, & Ostergaard, 2011).

### Medication Effectiveness

Even though there is no known cure for Parkinson's, there are medications that, when administered, help to at least manage symptoms. One medication has had great success since its implementation in the 1960's is known as Levodopa. Levodopa, when ingested, is converted into dopamine which is the neurotransmitter responsible for movement control and coordination (National Parkinson Foundation, 2013). Levodopa alone works well in managing symptoms of Parkinson's disease, but recent research indicates that adding in a second medication has proven to significantly reduce both symptom severity especially in those younger than 70-75 years of age (Schapira, 2005; Vu, Nutt, & Holford, 2012).

The current trajectory of Parkinson's guarantees that it will eventually require alterations to medications, medication schedules, lifestyle changes, and possible surgical interventions in order to combat both the symptoms and side effects of this disease (Platt, 2004; Vu, Nutt, & Holford, 2012). In early stages of Parkinson's, research has shown the effectiveness of medications in controlling symptoms. This period of effectiveness may last several years before the progression of the disease outruns the effectiveness of the medications (Burch & Sheerin, 2005; Vu, Nutt, & Holford, 2012).

Previous research suggests that, over time, Parkinson's medications become even less effective and symptoms may worsen (Vu, Nutt, & Holford, 2012). It has been reported by some that this feels like being trapped in an alien body unable to exert either command or control over what one does (Haahr, Kirkevold, Hall, & Ostergaard,

2011). Symptoms may progress slowly, however, given enough time, symptoms will progress faster than treatments are able to keep up, resulting in a person severely incapacitated and becoming more reliant on others for care (Barbas, 2006; Haahr, Kirkevold, Hall, & Ostergaard, 2010; Platt, 2004; Shapira, 2005; Vu, Nutt, & Holford, 2012).

### **Fatigue and Mental Health**

While fatigue and mental health concerns are common in many chronic illnesses, it is important to note how these factors affect those with Parkinson's disease. The amount of energy required for maintaining control over the physical body to accomplish the simplest of tasks may compound on one another, resulting in those with Parkinson's feeling exhausted (Poewe, 2008; Wressle, Engstrand & Granerus 2007). While mental concentration can be fatiguing in healthy people, it is more so for those dealing with Parkinson's. Due to destruction of neurons and synapses which results in cognitive slowing and states of confusion (and all other motor and non-motor symptoms), the amount of effort now used to conduct once basic of mental tasks can leave those with Parkinson's feeling exhausted after just a short time (Wressle, Engstrand, & Granerus, 2007). A significant contributing factor to fatigue is the high co-morbidity of sleep disturbances reported by those with Parkinson's (Alder, 2011; Boland & Stacy, 2012; Poewe, 2008; Shapira, 2005; Schreurs, De Ridder, & Bensing, 2000; Wressle, Engstrand, & Granerus, 2007). More often than not, sleep disturbances are reported as a side effect of Parkinson's disease and result from both motor and non-motor symptoms. These disturbances include difficulty falling asleep, waking up several times a night, and motor symptoms like restless leg syndrome or painful cramping (Adler, 2011; Poewe, 2008). As with many illnesses, doctors generally recommend getting plenty of rest, reducing stress, and limiting exhaustive daily activities as key components to reducing fatigue (Wressle, Engstrand & Granerus, 2007).

Mental health concerns are common to those living with a chronic illness like Parkinson's disease. The impact of depression should be noted as a significant factor affecting those with Parkinson's (Alder, 2011; Barbas, 2006; Borland & Stacy, 2012; Bucks, Cruise, Skinner, Loftus, Barker, & Thomas, 2011; Burch & Sheerin, 2005; Dobkin et. al., 2011; Janevic, Rosland, Wiitala, Connell, & Piette, 2012; McComb & Tickle-Degnen, 2005; McLaughlin et. al., 2010; Platt, 2004; Poewe, 2008; Schreurs, De Ridder, & Bensing, 2000; Wressle et. al., 2007). The relationship between depression and Parkinson's is like most chronic illnesses and has been found to be negatively correlated to one's quality of life, in that those who self-report higher levels of depression often indicate low perceptions in their quality of life (Bucks et. al., 2011;

McComb & Tickle-Degnen, 2005; Poewe, 2008; Schreurs et al., 2000; Wressle, et. al., 2007).

Areas of life that are examined when establishing changes in one's quality of life may include changes in social behavior, physical mobility, emotional wellbeing, stress, and social support (Borland & Stacy, 2012; Bucks et.al., 2011; Schreurs, De Ridder, & Bensing, 2000; Simpson, Haines, Lekwuwa, Wardle, & Crawford, 2006). Social support was identified as a significant correlating factor in the quality of life in those with Parkinson's disease on the PDQ-39 subscale (PDQ-39, or Parkinson's Disease Quality of Life Questionnaire, is a questionnaire used in evaluating different domains of life such as social support, communication, and stigma), in that higher levels of perceived social support significantly mitigated perceived depression, anxiety, and stress (McComb & Tickle-Degnen, 2005; Simpson, Haines, Lekwuwa, Wardle, & Crawford, 2006).

### **Burdens of Care and Social Isolation**

Often people with Parkinson's disease experience varying levels of reduced social interaction. When symptoms are unpredictable, it is not uncommon for those with Parkinson's to voluntarily reduce social outings due to fatigue, medication schedules, need for additional care, or out of fear of unwanted attention or embarrassment due to uncontrolled symptoms (McComb & Tickle-Degnen, 2005; Wressle, Engstrand & Granerus, 2007). This may be partly due to an insecurity or feeling hesitant in explaining their symptoms to others (Haahr, Kirkevold, Hall, & Ostergaard, 2011; McLaughlin et al., 2010; Platt, 2004; Wressle, Engstrand & Granerus, 2007).

Often when symptoms become unpredictable, a great deal of assistance is needed for daily activities and that reliance may result in one perceiving themselves as a burden on their caretakers (of which most are likely to be family members or spouses; Abendroth, Lutz, & Young, 2011; Boland & Stacy, 2012; Dobkin, et al., 2011; Haahr, Kirkevold, Hall, & Ostergaard, 2012; Janevic, Rosland, Wiitala, Connell, & Piette, 2012; McLaughlin et al., 2010; Platt, 2004; Wressle, Engstrand, & Granerus, 2007). As symptoms worsen and greater levels of care are needed public outings and visitors become less frequent, especially for those who are placed in a care facility due to caregiver fatigue, socioeconomic limitations, or the need for constant care (Abendroth, Lutz, & Young, 2011; Gallo & Matthews, 2003; Haahr, Kirkevold, Hall, & Ostergaard, 2010; McLaughlin et al., 2010; Platt, 2004; Wressle, Engstrand, & Granerus, 2007).

### **Burdens of Care and Family**

Changes in roles are often reported as the symptoms of Parkinson's progress. However, not all such changes were reported as being negative; some were reportedly a factor that helped to strengthen family bonds (Wressle, Engstrand, & Granerus, 2007). Many with Parkinson's

disease commonly report handing over responsibilities like cooking, paying the bills, or household chores to their families or spouses (Haahr, Kirkevold, Hall, & Ostergaard, 2011; McLaughlin et al., 2010; Platt, 2004; Wressle, Engstrand, & Granerus, 2007). In some cases, relationships with a family member or spouse who took on the primary role of caregiving were reported as strained due to the amount of time, resources, and difficulty of care required by some who live with Parkinson's (McLaughlin et al., 2010). An additional burden of care for family members who take on the role of an informal caregiver is that they may also report experiencing reduced socialization due to not wanting to leave their spouse or family member with Parkinson's alone for too long (McLaughlin et al., 2010; Wressle, Engstrand, & Granerus, 2007). If the care required by those with Parkinson's becomes too great for a family member or caregiver to maintain, the decision to institutionalize those with Parkinson's disease in a long-term care facility may seem like the only solution (Abendroth, Lutz, & Young, 2011; Haahr, Kirkevold, Hall, & Ostergaard, 2010; McLaughlin, et al., 2010; Platt, 2004; Wressle, Engstrand, & Granerus, 2007).

### **Burdens of Care; Financial Impact**

The quality of care one has access to is often the reflection of a means to pay for such care and, by extension, is often dictated by socioeconomic status (Gallo & Matthews, 2003). Current estimates for the amount of money spent on care for those with Parkinson's disease are around 23 billion dollars annually in the United States (Boland & Stacy, 2012). The economic burdens associated with the costs of care can be defined as lost wages, costs of prescription medications (often reported to be out of pocket expenses), and inpatient/outpatient care. These factors may impact decisions to institutionalize those with Parkinson's in to long-term care facilities (Boland & Stacy, 2012; Kaltenboeck, Johnson, Davis, Birnbaum, Carroll, Tarrants, & Siderowf, 2011; Platt, 2004). Findings in a report published by Kaltenboeck and colleagues (2011) on the direct costs of Medicare beneficiaries with early and advanced Parkinson's disease reported costs of care ranging from \$1500 per quarter to over \$8000 per quarter, depending on the amount of care required by those with Parkinson's disease. Additionally if families or care-givers have limited to no access to quality care due to socioeconomic status, out of pocket expenses can create unnecessary economic burdens economically for those with a chronic illness like Parkinson's disease (Boland & Stacy, 2012; Gallo & Matthews, 2003; McLaughlin et al., 2010).

The impact of this disease is clearly not limited to one's body by way of the brain. The impact of Parkinson's is evident in the total life experience of those with, and those involved with, this degenerative disease, and such impacts (motor/non-motor symptoms, medication

effectiveness, mental health, fatigue, social isolation, and family/informal care giver burnout) should be considered as symptoms of the overall Parkinson's experience and addressed accordingly.

### **Demographics**

The following section is a fictional character named Bill. Basic demographics are presented along with pertinent information spanning multiple domains of life. This information is helpful in determining appropriate courses of action to comprehensively treat Parkinson's and the person who lives with this disease.

**Name:** Bill

**Age:** 69

**Gender/ Ethnicity:** Male, White

**Family Dynamics:** Twice divorced, the second time after 15 years of marriage. Bill has no contact with ex-wife or plans of dating. Bill has one daughter from his first marriage, age 39, who is married with two children of her own. Both of Bill's parents are deceased as of three years ago and died within just a couple months of one another. Bill has had reduced contact with his daughter since his separation from her mother and recently had contact with his grandchildren reduced as well with due to differing opinions with his daughter over what to do with Bill's terminally ill parents while they were in the hospital. His daughter urged to allow natural death of Bill's parents while Bill wanted to continue treatment in spite of the urging of health care professionals that there would be little change for their quality of life to improve from further treatments. Bill was very close to his parents and in their last years had moved them into his house to help with daily care. Bill still has bouts of depression over their death and has kept their room as it was when they were alive. The current course of Parkinson's disease has Bill concerned over the status of his relationship with his daughter, and he wants increased contact with both his daughter and grandchildren.

**Occupation:** Retired from a county appraiser position a year after his parents died. Bill waited to retire until his parent's life insurance paid out, all medical debts were settled, and his home mortgage was paid in full. During the last years of work Bill had to continuously reduce his hours and work load due to increased fatigue brought on in the early stages of Parkinson's. Now, Bill spends most of his time at home watching TV, going to medical appointments, or occasionally visiting a friend that lives nearby.

**SES:** Retired, but makes enough money from a retirement fund and social security to not have to worry about bills as long as he stays within his current budget. Bill lives a modest lifestyle due to his fixed income but is

still able to occasionally eat lunch out and buy small gifts for his grandchildren. His monthly expenses are limited and include things like a cell phone (daughter's idea), basic cable, and car insurance for the car he has owned for the last 10 years. His parent's life insurance was used up to pay medical expenses prior to their deaths, cover funeral expenses, as well as pay off the mortgage on Bill's house. Without the life insurance to cover these expenses Bill would not have been able to afford to live on his own.

**Living Arrangements:** Bill owns his single level home and lives on the other side of town from his daughter. He has a friend that lives nearby and occasionally checks on him to see how he is doing, but he is stopping by less frequently as Bill's symptoms progress. Bill suspects that his friend may not be sure how to handle the changes in his cognition as well as seeing the physical symptoms, like tremors, associated with Parkinson's disease. His friend is most likely unsure how to assimilate Bill's changes in to his schema of whom Bill should be and is distancing himself from the source of what is making him uncomfortable. Bill is still able to conduct all necessary activities of daily living (ADL's), such as cooking, cleaning, bathing, and grooming, but has started to notice a reduced ability in fine motor skills making it difficult to operate button-up shirts and has opted to wearing simple clothes that do not require much effort to put on.

**Emotional State of Mind:** Bill has concerns over the progression of his symptoms and worries about future cognition declines as he occasionally forgets exactly what he was doing and why he went into a room. Even though his condition will eventually require greater amounts of assistance, Bill is reluctant to give up the independence he has been used to his entire adult life. Bill contemplates the idea of eventually moving to a skilled nursing facility when he is no longer able to safely live alone but would rather live with family and have them assist with care. The main barrier Bill feels to moving in with his daughter and her family is the current status of the family relationship and the reduced contact.

Bill was in denial of his symptoms for several years before diagnosis. His reluctance to accept that something was wrong was due to the slow onset of physical symptoms and mistakenly attributing symptoms to the decline of natural aging. Finally after the urging of family and his friend Walter, Bill finally acknowledged his physical and cognitive changes and went to see his doctor who, with the help of a neurologist, eventually diagnosed Bill with Parkinson's disease.

As physical and cognitive symptoms progress, Bill has bouts of anger, resentment, and sadness. Bill is angry with his symptoms and feels as though his identity is disappearing more and more as his physical and cognitive abilities decline. He also fears that his dignity will one day be gone and feels saddened by the thought of having to

rely on someone to wipe drool from his chin or dress him like a child. Due to everything that has gone on the last few years (diagnosis of Parkinson's, death of his parents, the continued strain of family relationships), Bill suffers from depression, a common co-morbidity found in those living with a chronic illness. A major source of Bill's depression centers on the idea that as his symptoms progress he will lose more and more of who he used to be and will eventually be a burden on others.

**Health Care Access:** Bill now relies on Medicare and sometimes has to pay for services and medications out of pocket due to his loss of insurance that would have covered his current medical expenses. Bill had the opportunity to continue coverage through this insurance but found it to be too expensive for his retirement budget. Bill visits his doctor every other month, and as needed when symptoms are worse, to see how the Parkinson's medication as well as the medication for depression is working. Based on the recommendation from his physician, Bill is seeing both a physical therapist as well as an occupational therapist. Bill visits an outpatient rehabilitation clinic for his physical therapy and occupational therapy appointments and perceives to have significant success in limiting declines in physical abilities. Their appointment coordinator works to ensure that Bill's appointments are back to back on the same day to reduce the need for frequent trips during the week to the clinic.

Bill's physician is also discussing options for future care to help ease the pain sometimes associated with physical symptoms like rigidity. One option his physician recommends is that Bill speaks to palliative care specialist in the near future to discuss and coordinate treatment options for specific needs as the progressive nature of this disease is certain.

**Choice of Treatment(s):** Bill has chosen to take medications as prescribed by his physician and to take part in physical and occupation therapy to treat the symptoms of Parkinson's. Bill's physician, along with his neurologist, works to maintain the right combination of medications that will best treat the symptoms of Parkinson's as well as the depression Bill now suffers from. Bill relies on the successes and interactions at the outpatient rehabilitation clinic to maintain his optimism for treatment during his adjustment to new medication levels, which may leave him feeling less in control over his symptoms.

**Advance Directive/POLST:** Bill had an advance directive filed with his doctor's office several years ago. However, due to the diagnosis of Parkinson's, advancement of symptoms, and urging from his physician, Bill has an updated version in place that reflects an overall desire to maintain dignity. Bill's POLST also reflects his desire for dignity in that he wishes that all life saving measures

(CPR, feeding tubes, and transportation to a hospital for further care) are used to continue life.

### Specific Support Strategies

Assuming a starting point of Bill's diagnosis, the following section will discuss specific support strategies based on evidence and research. The goal is to comprehensively treat Bill for both Parkinson's and address parts of Bill's life as integrated parts of his Parkinson's experience.

#### Bill's Physician

At the time of a successful diagnosis of Parkinson's disease, Bill will likely have had various possible emotional shifts in mood like relief, fear, or disbelief. Bill's physician, if keen to these shifts, should take the time to address any concerns and discuss with Bill what a diagnosis of Parkinson's disease actually means. The task of educating Bill about what it means to live with Parkinson's disease or discussing all available resources for assistance may be too much for one appointment, so additional office visits may be recommended. Bill's physician should be at least able give Bill the basics of what this incurable disease does to the physical body as well as the mind. He should also discuss symptoms that may appear later, treatment options, and decide on a plan of action for treating Bill specifically.

Monitoring the success of Bill's medication regime will be the job of both Bill and his physician. The need for effective communication between Bill and his physician regarding how well Bill's medication(s) control his symptoms is crucial so Bill doesn't suffer side effects of incorrectly prescribed medications. Such side effects may include nausea, vomiting, confusion, or experiencing unnecessary physical symptoms like involuntary or erratic movements (National Parkinson Foundation, 2013).

Bill's physician will also need to direct Bill to other sources for information for Parkinson's disease, including a neurologist, local associations who deal with Parkinson's, support groups, outpatient rehabilitation therapy, and a social worker/case manager. Most important are the referrals to a social worker/case manager and an outpatient rehabilitation therapist. Social workers or case managers are individual who have been trained in handling multiple facets of an illness experience, and these individuals can provide answers to questions about access to health care, and access additional resources helpful to Bill beyond the medical treatment of his disease. The professionals at an outpatient rehabilitation clinic are physical therapists, occupational therapists, as well as speech therapists, all of which may be useful to someone living with Parkinson's disease (Ransmayr, 2011).

#### Social Worker or Case Manager

Areas of focus that a social worker or case manager should be concerned with are Bill's perceived social support and depression. Evidence has shown a significant correlation to perceived social support on both health related outcomes and quality of life (Bucks et al., 2011; Cohen, Underwood, & Gottlieb, 2000; McComb & Tickle-Degnen, 2005; Schreurs, De Ridder, & Bensing, 2000; Simpson, Haines, Lekwuwa, Wardle, & Crawford, 2006; Wressle et al., 2007). Another area of focus that needs to be addressed is depression, as it too has been indicated to be a significant factor in health-related outcomes, as well as quality of life (Alder, 2011; Barbas, 2006; Borland & Stacy, 2012; Bucks et al., 2011; Burch & Sheerin, 2005; Dobkin et al., 2011; Janevic, Rosland, Wiitala, Connell, & Piette, 2012; McComb & Tickle-Degnen, 2005; McLaughlin et al., 2010; Platt, 2004; Poewe, 2008; Schreurs, De Ridder, & Bensing, 2000; Wressle et al., 2007)

Since Bill has expressed feelings of depression and voiced concern about his relationship with his family, a social worker or case manager should encourage Bill to speak to a therapist regarding these issues. A therapist, in addressing Bill's depression, should use cognitive behavioral therapy (CBT) along with medications to treat depression prescribed by a physician. Evidence indicates that when CBT and medication are combined, depression is significantly reduced more so than when medication therapy is used alone (Dobkin et al, 2011).

For Bill's concern over his relationship with his daughter a therapist should attempt to include family members, if willing, in counseling to address events that have led to the current family dynamic. As previously mentioned, Bill and his daughter disagreed on end of life issues for Bill's parents and those disagreements resulted in decreased communication between the two. The lack of communication may have added to Bill's increased perceptions of social isolation as well as incidence of depression. There is research to suggest that relatives are more willing to assist in the care of family members when there are reports of depression (Janevic, Rosland, Wiitala, Connell, & Piette, 2012). This means that Bills daughter may be more willing to participate and help with Bill's care, to include counseling, if Bill's condition (Parkinson's and depression) is shared openly. Increased participation from Bill's daughter will not only help Bill receive needed assistance for medically related care but will also address issues like perceived social support, social isolation, and help mitigate symptoms of depression. However, there are risks to those who take the role of an informal care giver that should be presented to Bill and his daughter. Such risks include those who provide care may also experience decreased social isolation and incidence of depression (McLaughlin et al., 2010; Platt, 2004). Another concern is over the incidence of informal caregiver strain due to the amount of time and resources needed by those who live with Parkinson's disease (McLaughlin et al., 2010;



Platt, 2004; Wressle, Engstrand, & Granerus, 2007). A well-trained social worker or case manager needs to inform families of these risks and provide resources, if available, to help mitigate such risks so Bill and his family are better prepared for the long term burdens of providing assistance to someone with a chronic illness like Parkinson's disease.

### Outpatient Rehabilitation Specialist

Physical, occupational, and speech therapy are used to help reduce the progress of symptoms associated with Parkinson's disease (Ransmayr, 2011). Quantitative evidence is lacking as to the benefits of physical and occupational therapy, however significant improvements have been documented with the use of speech therapy in those with Parkinson's. While research examining the effects of physical and occupational therapy in the treatment of Parkinson's remain inconclusive in regards to their impact on the disease itself, both patients and their caregivers indicate significant improvements in their perceived health-related quality of life (Ransmayr, 2011; Sturkenboom, Graff, Borm, Veenhuizen, Bloem, Munneke, & Nijhuis-van der Sanden, 2012; Wressle, Engstrand, & Granerus, 2007). Given reports of both physical therapy and occupational therapy resulting in positive impacts related to quality of life factors, continued use of these therapies is recommended.

### Conclusion

A life with Parkinson's disease is a life of predictable uncertainty. Not every experience of Parkinson's can be summarized by a single story. The symptoms of Parkinson's that present do so in a variety of manners which require specific interventions. However, there are threads of this incurable disease that are commonly shared. This hypothetical case study addresses several of these commonalities those with Parkinson's disease may experience across multiple domains like one's social, emotional and biological aspects of life. In recognizing common experiences shared by those with Parkinson's, care providers can incorporate interventions designed to address a person's life in a holistic manner in an effort to minimize negative impacts of one's Parkinson's experience.

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